

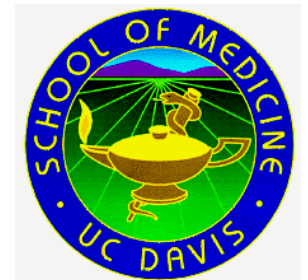


# Talking to Your Loved One's Doctors

## Strategies for Successful Communication



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# Talking to Your Loved One's Doctors

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- The difficult transitions
- What the caregiver can offer to the medical team
- Overcoming obstacles
- Learning to work together
- Resources and HD Care Kit

# Huntington's Disease Stages

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- Stage 0: Presymptomatic
- Stage 1: Slightly lower performance at work and home; independent at home
- Stage 2: Can still work (lower level), still mostly independent at home
- Stage 3: Difficult to work, starts to need help with financial, home activities
- Stage 4: Unable to work. Needs major assistance with care
- Stage 5: Full-time nursing care required

*Adapted from Shoulson et al, Quantification of Neurological Deficit,  
Boston:Butterworth, 1989*

# Difficult Transitions

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- The transition from health to early HD
- Poorer performance at work and home
- Qualifying for disability
- Is it still safe to drive?
- Increasing needs for caregiving and supervision
- Later stage care needs

# The Features of HD May Make the Transitions More Difficult

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- Unawareness of symptoms on the part of the person with HD
- Cognitive and behavioral changes may appear before movement disorders in early HD
- Although movement-related and thinking changes progress predictably, psychiatric and emotional changes are often quite unpredictable
- The desire to maintain independence vs. the increasing need for care may become a source of conflict

# Caregiving – *It's Not Easy!*

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- As a family caregiver, you are an essential partner in your loved one's treatment.
- Caregiving challenges change throughout the course of HD.
- Your input and communication with the medical team can improve quality of care and quality of life for your loved one - *and yourself!*
- *Share the care – it's never too early to seek help.*

## Challenges – “*Is it HD?*”

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- Symptoms of depression or anxiety can mimic early-stage HD.
  - Whether it's HD or not, those symptoms are treatable!
- “Honey, I think we need to see the doctor.”
  - Very difficult conversation to initiate; remember that the person with HD may not be aware of their symptoms.

## Challenges – “*Show me*”

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Doctors may not appreciate the symptoms and signs of early HD

- While movement disorders are visible, it can be difficult to see changes in behavior and cognition
- Emotional outbursts are unpredictable and the doctor may never see the behaviors you see
- Doctors may feel that the caregiver is being emotional and that symptoms are being exaggerated



## Challenges – *"Do you hear me?"*

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- Time limits at medical appointments
  - In a typical medical appointment, you have about 7 minutes with the doctor
- Limited communication with the doctor can create situations where the progression of the disease is not being acknowledged
- Treatable symptoms like depression and anxiety may be overlooked or not addressed fully
- You may feel ignored and alone

# Building Credibility – Being Believed

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As a family caregiver, you are an essential partner in your loved one's treatment.

- How can you bring important symptoms to the attention of the medical team?
- How do you get them to listen to you?

# Building Credibility – Being Believed

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*Be prepared!*

- Understand the symptoms of HD
- Keep track of symptoms
- Come to the appointment with questions
- Ask for action and follow up

# Keeping Track of Symptoms

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- Keep an incident log of symptoms – include the dates of outbursts, impulsivity, aggression, etc.
- Make a note of conversations you have had with the doctor – for example, when you first brought a symptom to their attention
- Keep a current list of your loved one's medications and any side effects you have observed.
- Write down your questions as they come to you – you cannot assume you will remember them

# Building Credibility – Being Believed

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- Bring a one-page summary of symptoms with you to the appointment – specific dates and examples of changes in abilities and daily function are most helpful
- The log will help the doctor see the behavior patterns that you see and help establish cognitive and behavioral impairments for determination of disability
- Ask the physician to include the changes you've noted in the visit record and office notes

# Building Credibility – Being Believed

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- The process may be frustrating, but try to avoid getting angry. Use facts.
- Call your nearest HDSA Center of Excellence for advice if you live too far away to be seen there.
- Ask for referrals to Neurology, Psychiatry if needed.
- In some cases, you may need to seek a second opinion from a different doctor.

# Asking for Action

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- At the end of an appointment, repeat what you and the doctor have decided on, for example:
  - Starting or changing medication
  - Changes in nutrition
  - Recommendations for psychiatric evaluation or counseling
  - Recommendations for allied health assessments such as physical therapy
  
- At the next appointment, follow up or report results.

# Asking for Evaluations/Assessments

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- Referral to a neurologist
  - Initial diagnosis
  - Management of chorea or motor symptoms
- Referral (or self-referral) to a therapist
  - Supportive counseling at initial diagnosis or advancing stages
  - To help treat mild-moderate depression, anxiety or behavioral difficulties
- Referral to a psychiatrist
  - Frequent or severe irritability/anger
  - Symptoms of depression, anxiety, OCD or psychosis

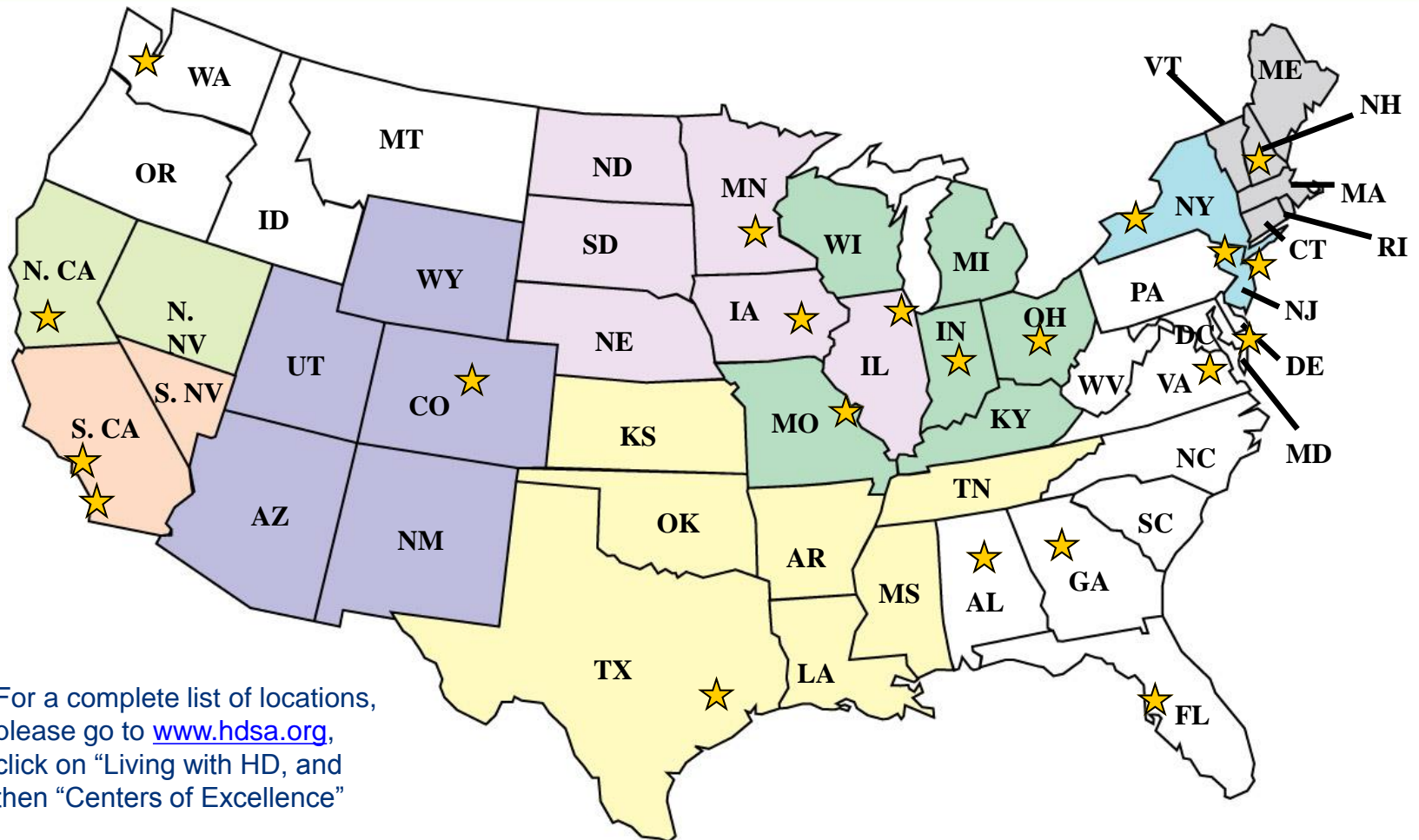


# Additional Assessments

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- Occupational therapy
  - Exercises or adaptive equipment for activities of daily living related to hand function
- Physical therapy
  - Teach functional/balance exercises
  - Evaluate gait difficulties and need for home mobility equipment
- Speech and language therapist
  - Swallow and/or speech difficulties
- Dietician or nutritionist
  - For weight loss (or gain), dietary changes for swallowing difficulties

# 21 HDSA Centers of Excellence



For a complete list of locations, please go to [www.hdsa.org](http://www.hdsa.org), click on "Living with HD, and then "Centers of Excellence"

# HDSA Centers of Excellence

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- These are designated centers for accessible and expert diagnosis and care for HD.
- Core personnel include neurologist, social worker, nurse and other medical professionals
- Personnel are available by phone to speak to patients, families and other health care providers
- Center of Excellence Social Workers are excellent resources for referrals to specialists, information about disability, caregiver support and care facilities.

# Local HDSA Chapters and Support Groups

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- Many Chapters have social workers who can help in many ways.
- Chapters can put you in touch with other families affected by HD, who can be excellent resources for finding medical professionals and for providing caregiver support.
- Listings are available on the HDSA website, [www.hdsa.org](http://www.hdsa.org)

# Creating an HD Care Kit

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- As HD progresses, there may come a time of crisis, when your loved one comes in contact with law enforcement or emergency medical personnel.
- Having an HD CARE Kit of important numbers and documents may help you to prevent dangerous misunderstandings during this encounter.
- HD Care Kit forms - can be downloaded by clicking on the link that will appear with this webinar when it appears on the HDSA national web site.

# Creating an HD Care Kit

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The CARE kit should contains these important documents:

- List of emergency numbers
- One-page psychiatric history summary
- Recent picture and description
- Copy of criteria for emergency evaluation
- Copy of criteria for civil commitment
- Petition form for emergency evaluation
- Petition form for civil commitment
- Signed Medical release
- Medical Power of Attorney
- Patient's Advance directive

# Working Together

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- By learning how to communicate with medical professionals, you can help improve the care of your loved one with HD
- Medical professionals may also be able to help the person with HD to be more responsive and cooperative at home –

*Sometimes they just need to hear it from someone other than their caregiver*

# Finally, Don't Forget ... *Yourself!*

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- Your loved one is not the only one who may need a doctor's care
- Your health and well-being are essential if you are to look after your loved one
- A therapist may become an important part of your medical team
- Make time to take care of yourself. Look into respite services.



# The HDSA Website: [www.hdsa.org](http://www.hdsa.org)

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The HDSA website can put you in touch with people who are there to help –

- HDSA Centers of Excellence
- Support groups in your local area
- Your local HDSA chapter
- HDSA Social Workers